Title: Reviewing Treatment Guidelines

Description: In this breakout group we will review a draft of the proposed treatment guidelines.

These are the guidelines we propose, based on literature review, focus groups, and feedback from stakeholders. The audience of this draft is for clinicians. The goal is to avoid overly formal language, but may not be fully clear language. In the future, we will work with DEEP to develop a clear language version for adults with ID and their families.

Questions for breakout discussion:

In each section, is the tone and message appropriate?

Are we missing any topics within existing sections?

Are we missing any key concepts?

Are there resources or examples that you think would be helpful to include?

Plan for final version is brief text description and links to additional resources and examples. We will also include citations. We are also currently proposing to write a more detailed book with additional research citations, examples of how to apply, and resources.

General Ethics Considerations

1. Guard against and discrimination based on individual's disability or associated characteristics.
    - This includes self-examination of beliefs and experiences, and increasing knowledge on disability terminology and characteristics of ableism.
    - Therapists should be aware of their own explicit or implicit biases that may impact how they interact with individuals with ID and their support people.
2. Ensure that informed consent is obtained from the individual.
    - It is important that the adult with IDD feel empowered to make decisions about their own mental health care.
    - This should be obtained even if the adult is not their own guardian. Be familiar with the different levels of guardianship available (we will provide resource)

3. Obtain appropriate permission to release information before discussing any aspects of the individual's care.
    - Permission should be obtain from individual **and** guardian (if applicable).
    - This should be done at the onset of therapy, but should also be continued in an ongoing manner throughout the therapeutic relationship.
4. Prioritize and always consider the adult with ID's preferences. The adult with ID is the client.
    - Contradictory preferences of support people and/or parents/guardians should be discussed among the group but should not be seen automatically as taking precedence.
5. Choose appropriate materials based not only on the individual's language level and/or cognitive level, but also considering their age.
    - Avoid Infantizing. That is do not treat an adult with ID like a child. This denies their maturity and experience.

Rapport Building/Maintaining

1. Treat clients with ID with integrity and respect. Create an environment where individuals with ID have a safe place to talk with someone who listens to them and values what they have to say.
2. Communicate investment in the person as a whole through verbal and nonverbal communication and behavior
3. Communicate to the client that what they think and feel is important.
4. Assess unique needs of each person and employing strategies using their strength and preferences to guide interactions
5. Use interests to build relationship between therapist and individual and support therapy
6. Meet clients where they are linguistically and cognitively; structure therapy to maximize their participation and comfort based on this information

Self-determination and advocacy

1. Empower adults with ID to have agency in the therapeutic process
2. Empowering clients with ID to make decisions in regard to confidentiality and disclosure
3. Teach clients with ID to advocate, by practicing in therapy and modeling
    i. An example: Client as teacher to team/supports/staff; showing their team they can advocate

Structure of Therapy and Goals

Clinicians should be thoughtful about all aspects of the structure of therapy.

1. This begins with ensuring they are obtaining informed consent, understanding the client's motivation to participate, and collaboratively establishing goals.
    - Understanding the client's interest in therapy is key, as it is often support people or other providers who have referred the adult with ID to therapy.
2. Tailor therapy modalities, strategies, and tools to the abilities, needs, and preferences of a client with IDD; keep in mind barriers due to cognitive limitations, visual impairments, gross or fine motor impairments, etc.
3. Consideration of time is key with the IDD population: sufficient time to process questions, optimal session lengths (i.e., shorter vs. longer), and broadly, time needed to build a solid relationship before beginning therapeutic content.
4. A successful use of time in therapy may require providers to be more directive and design more structured sessions.
5. Providers should regularly communicate with clients about any changes in their preferences to promote ongoing consent, particularly regarding involvement of support people in therapy.
6. It would benefit providers to explicitly communicate with clients about the use and type of accommodations which will enable them to participate fully in therapy

Assessment

1. Assessment of client's needs and preferences can help to guide planning for the structure of therapy, inclusion of caregivers, communication, and adaptations.
2. Assessment at the start of and throughout therapy can be helpful for the clinicians to meet the client where they are in communication and adaptations.
3. Assessment to determining goal attainment/progress: Assessment may be helpful in determining to what extent the client is meeting goals; as well as to what extend do they feel they are meeting their goals.
4. Whenever possible use of instruments validated in ID population
5. If not available, Providers may need to be mindful of providing appropriate accommodations when using assessments to ensure they are obtaining accurate results
    - Accommodations may include reading items out loud, translating items to more simple language, giving examples, and using visual aids. See accommodation guideline for additional details.

6. An assessment of the support person(s) understanding of mental health and expectations of therapy may be helpful in guiding necessary psychoeducation.

Accommodation and Support within Therapy

1. There is very little data on comparative use of different types of accommodations and supports in therapy; therefore, use of accommodations should be evidence-based AND informed by client assessment and preferences.
2. Many accommodations are described in the literature and have some support as a part of larger treatment manuals/packages. Many adults with ID prefer visual supports, but others may have visual impairments or find verbal information or kinesthetic activities more helpful. Examples Include:
    i. INSERT EXAMPLES FROM SCOPING REVIEW
3. When using any type of accommodation or visual support, ensure that clear/plain language is used and that the document is accessible regarding not only content, but also text; many adults with ID use text to speech technology to assist with reading which require specific formats.

Communication

1. Use assessments to inform language and communication strengths and areas for support.
2. It can be helpful to break down more complex concepts and make them more concrete when possible.
3. Clinicians should incorporate in any assistive technology that a client has, such as an augmentative alternative communication (AAC) device.
4. Give clients with ID adequate, and additional time if necessary, to formulate an answer when asking questions
    - Clients with ID value clinicians who allow adequate time for client to respond to questions.
    - Encourage them to use their AAC device if applicable.
5. Providing materials for client to review between session can help.
6. Avoid stigmatizing language (e.g., special needs).
7. Professional communication should be that which uses appropriate person-first or disability-first language as preferred by their client.

Involving Support People

Involving support people in therapy can be useful. Support people can help to facilitate communication, put the client at ease, and aid in the generalization of skills outside of therapy. There are several important considerations when including them.

1. Provide psychoeducation to the support person on mental health and therapy
2. Work with support people to set appropriate expectations.
3. Differentiate the client's needs and goals from those of the support person.
4. Be sure that permission to include support people is given by the client and then regularly check in to ensure the client has not changed his or her mind.
5. Be thoughtful in how and when support people are included in therapy.
6. Set up expectation to have a consistent support person attend appointments.
    - Be mindful that support staff turnover can be challenging;

Other Considerations

Need to consider cultural variability and other considerations. Do you have specific recommendations here?